EXECUTIVE SUMMARY

NATIVE OUTREACH

A Report to American Indian, Alaska Native, and Native Hawaiian Communities

NATIONAL INSTITUTES OF HEALTH

NATIONAL CANCER INSTITUTE

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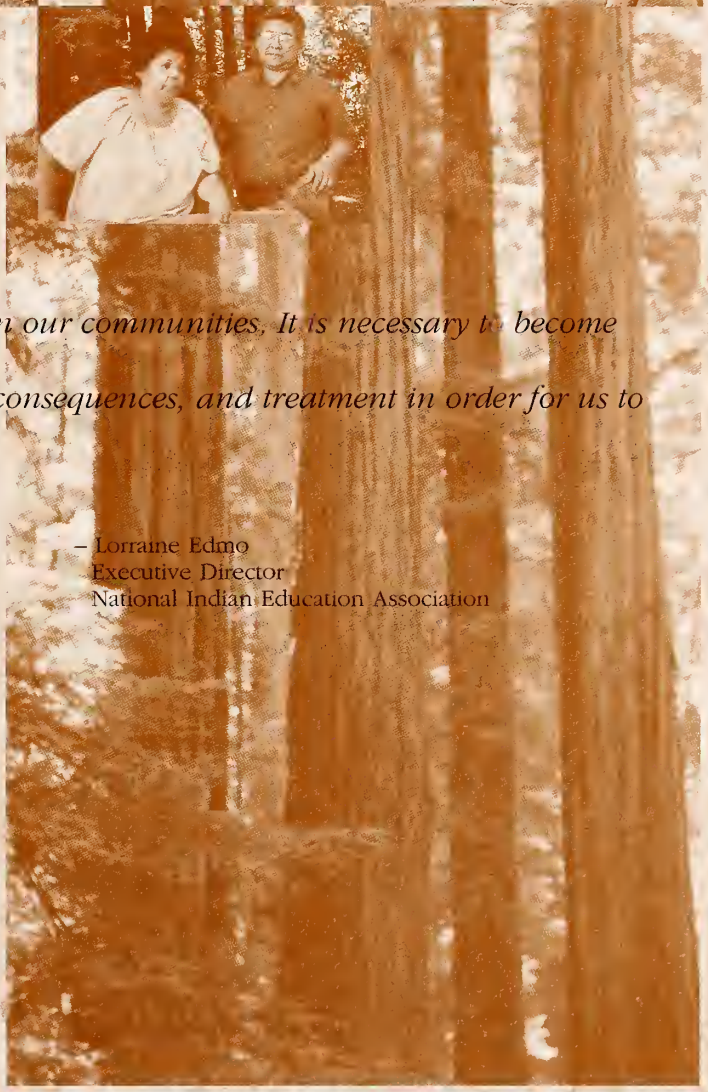

"Cancer is rapidly becoming a serious threat in our communities. It is necessary to become more familiar with this threat and its causes, consequences, and treatment in order for us to successfully combat this disease."

– Lorraine Edmo
Executive Director
National Indian Education Association

Foreword

The National Cancer Institute (NCI) is pleased to present *Native Outreach: A Report to American Indian, Alaska Native, and Native Hawaiian Communities*—a monograph written specifically for community leaders, health professionals, and lay health workers serving those communities. Native Americans have higher mortality rates than the general U.S. population for several major cancer sites. *Native Outreach* focuses on the need to reduce those rates through effective interventions at the grassroots level.

NCI's mission, to conduct a comprehensive program of research to discover ways to reduce the burden of cancer, drives one of its primary goals—to translate tested methods for cancer prevention and control into tangible benefits for American communities. In the NCI Division of Cancer Control and Population Sciences, culturally sensitive methods for cancer prevention and control are being developed and tested for special populations. Through this monograph, we disseminate information arising from NCI research focused on Native Americans and their cancer control needs.

Today, we know that cancer is a group of diseases that results from a series of changes in genes that control cell growth and behavior. These genetic changes transform healthy cells into cancerous cells. The relationship of such genetic changes to the environment and to behaviors such as smoking and consumption of a diet high in fat is particularly relevant to cancer prevention. Environmental risks associated with smoking, diet, the community, workplace, and so on, probably account for more than 50 percent of all cancer cases. Smoking is the most preventable cause of death in the United States. Tobacco use is responsible for almost one in five deaths and accounts for nearly 30 percent of all cancer deaths in the United States. Similarly, scientists suggest that about one-third of U.S. cancer deaths each year are attributable to dietary factors. From another perspective on cancer control, we know that early detection of some cancers, such as those of the breast and cervix, can significantly improve cancer survival and reduce cancer mortality.

The *Native Outreach* monograph summarizes interventions designed to reduce cancer rates through studies focusing on breast and cervical cancers, education and screening, tobacco education and policy, smoking cessation and prevention, and nutrition education for Native Americans. In this volume, we document the planning, development, implementation, and evaluation of seven studies carried out between 1989 and 1996 from two of our Native American research programs: Avoidable Mortality From Cancer in Native American Populations and Primary Prevention of Cancer in Native American Populations. These studies identified key factors contributing to avoidable mortality from breast and cervical cancers, implemented programs to increase screening for these cancers, and focused on innovative interventions to eliminate or reduce cancer risks from tobacco and diet.

We encourage readers to use this volume as a guide for designing culture-appropriate, community-level activities. Whatever your needs are, we fervently hope that *Native Outreach* will provide adequate assistance and that your cancer control programs will be effective, ultimately reducing cancer's toll in your community.

Richard D. Klausner, M.D.
Director, National Cancer Institute

Preface

This publication, *Native Outreach: A Report to American Indian, Alaska Native, and Native Hawaiian Communities*, is significant as it provides needed information on program implementation and data to our Native people. Cancer is rapidly becoming a serious threat in our communities. It is necessary to become more familiar with this threat and its causes, consequences, and treatment in order for us to successfully combat this disease.

This publication contains information not only on the morbidity and mortality of cancers in Native communities but also on projects that are successful and culturally relevant to our communities. This is an important and valuable contribution to our Native people, as it provides information and models that can be referenced and replicated. This is a necessary step in addressing the health of our communities and in helping us set up our own programs.

This manuscript is the first of its kind. It is designed to provide essential information to the Native population regarding the problem of cancer in our communities and the identification of what works in cancer prevention and control. Thanks to each of the researchers involved in these projects for their dedication and hard work in cancer control efforts in our American Indian, Alaska Native, and Native Hawaiian communities.

Lorraine Edmo
Executive Director
National Indian Education Association

Acknowledgments

The editors wish to thank the authors of this monograph and the principal investigators and co-investigators of the Avoidable Mortality From Cancer in Native American Populations Program and the Primary Prevention of Cancer in Native American Populations Program for their support of and commitment to this monograph. We also thank Drs. Larri Fredericks (Athabascan) (Center for American Indian Research and Education [CAIRE]) and Noma Roberson (Roswell Park Memorial Cancer Institute), who served as special reviewers and assistant editors of the monograph. This monograph would not have been possible without their dedication and hard work. We thank the following reviewers of the monograph for their astute comments and suggestions: Beverly Rodriguez (Pomo); Barry Miller and Drs. Otis Brawley, Nancy Breen, and Susan Devesa (National Cancer Institute [NCI]); June Strickland (Cherokee) (University of Washington); and Anthony Garcia (Apache) (University of California at Berkeley).

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INTRODUCTION

This monograph presents the National Cancer Institute's (NCI) research efforts in Native American communities reported primarily to community leaders, health professionals, and lay health workers. As a result of targeted efforts, eight cooperative agreements were funded to design, develop, implement, and evaluate interventions in cancer prevention and control. These studies are historic because they represent the first concerted nationwide effort by NCI to address the cancer prevention and control needs of Native Americans. Although these studies were funded to enhance cancer prevention and control research and programs in Native American communities, they also can be used as valuable models for encouraging Native American community leaders, health professionals, and lay health workers to implement these types of studies in their native communities.

For several years, NCI has taken steps to reduce the impact of cancer in Native American communities. In 1989, NCI invited investigators to apply for cooperative agreements to assess, with NCI's assistance, the effectiveness of cancer prevention and control intervention strategies in Native American populations, defined as American Indians, Alaska Natives, and Native Hawaiians. Two Requests for Applications (RFAs) were issued. Subsequently, NCI funded eight studies: four under the Avoidable Mortality From Cancer in Native American Populations RFA and four under the Primary Prevention of Cancer in Native American Populations RFA. These studies were conducted between 1989 and 1996. This monograph documents findings from seven of the eight studies. (For this monograph, references to all three Native American subpopulations are indicated by the term "Native Americans" unless otherwise noted.)

Although the goals of the avoidable mortality and primary prevention programs were similar in that they both addressed cancer prevention and control efforts in Native American communities, they differed in their approach. The Avoidable Mortality From Cancer in Native American Populations program addressed the effectiveness and efficacy of cancer prevention and control intervention strategies to increase appropriate use of screening procedures to reduce cancer rates and risks among Native Americans. Simply stated, these goals were to:

- Identify key factors that contribute to avoidable mortality from specific cancers, such as cervical and breast cancers;
- Increase appropriate use of screening procedures to reduce the rates of these cancers and/or risks; and
- Evaluate the effectiveness of these interventions.

Avoidable mortality interventions are characterized by methods that help people overcome barriers to cancer prevention and control services. Typically, these barriers include behavioral/cultural barriers and health system/structural barriers. Behavioral/cultural barriers encompass language differences, psychosocial factors, cultural beliefs that may influence accessing cancer control services, and lack of knowledge and understanding of cancer prevention and control services. Health system/structural barriers include availability of cancer control services, financial limitations, and transportation problems.

The goals of the Primary Prevention of Cancer in Native American Populations program were to:

- Develop innovative smoking and smokeless tobacco use prevention and cessation and/or dietary intervention programs; and
- Determine the long-term effectiveness of these programs.

Primary prevention is the complete avoidance of exposure to a carcinogen *(1)*. Primary prevention also includes efforts to identify and modify behaviors and attitudes that have been recognized as risk factors for cancer. Primary prevention interventions are characterized by behavioral studies aimed at smoking prevention and cessation to prevent the onset of smoking behavior or to stop smoking behavior before it results in a person developing cancer. In addition, primary prevention interventions include nutrition studies that focus on modifying dietary behavior.

MAJOR FINDINGS OF THE RESEARCH STUDIES

- The incidence of cervical cancer is of significant concern in the Native American community.
- American Indians and Alaska Natives have extremely high cigarette smoking prevalence rates. Targeted interventions require culturally appropriate and community-based programs to address this problem.
- Tobacco abuse among American Indian teens is increasing and requires immediate attention.
- Cancer incidence and mortality data are needed for a larger cross section of the American Indian population to more accurately evaluate the cancer burden in this population.
- Cultural sensitivity was a hallmark characteristic of the Native American research studies.
- Significant involvement of Native American researchers, staff, advisors, and community leaders enhanced the success of the research studies as Native Americans were involved in all phases of the studies.

PURPOSE OF THE MONOGRAPH

This monograph documents findings from the NCI's Native American cancer prevention and control research studies. It is designed and written primarily for Native American community leaders, health professionals, and lay health workers to promote cancer prevention and control activities at the community level. It also highlights the exciting collaborative efforts between American Indian, Alaska Native, and Native Hawaiian researchers—as well as others who are experienced in Native American research in cancer prevention and control—and NCI. This monograph's unique presentation includes research studies that employed a number of research designs (i.e., randomized clinical trials, Solomon Four-Group Design *(2)*, and pretest-posttest design) and intervention approaches (i.e., policy, educational, behavioral, and replication) to address cancer prevention and control programs for Native Americans.

Findings from the research studies are important because they increase our understanding of methods that may be successful in Native American communities. The methods discussed here are models for developing successful cancer prevention and control programs in Native American communities. These studies have shown that conducting interventions in Native American communities requires the cooperation and involvement of the community in all phases of the health-promoting activity for it to be successful and culturally appropriate. In addition, this monograph documents the need for Native American communities to promote further investigation in the area of cancer prevention and control.

This monograph is organized into nine chapters: an introductory chapter, seven chapters that describe each of the studies in detail, and a concluding chapter. Three of the chapters describe the avoidable mortality studies, and four chapters describe the primary prevention studies, respectively. The final chapter of the monograph summarizes the studies and discusses the four research intervention approaches utilized by the research teams: policy change, behavior change, education, and replication. A policy is an overall plan that supports the general goals and acceptable procedures of a governmental body. The implementation of a new or revised policy is often the most difficult, because designing and implementing policies is a lengthy procedure requiring collaboration. Behavior change influences an individual's or group's response or action. Education increases an individual's level of knowledge. Replication of proven intervention models is a more common approach to addressing community health needs. In many cases, using a previously tested intervention reduces the overall planning and development stages of the study.

NATIVE AMERICANS AND CANCER: THE NEED FOR SPECIAL STUDIES

One of NCI's goals is to ensure that the burden of cancer is reduced in all communities, including Native American communities. The history of NCI reflects that commitment.

NCI is the premier cancer research agency of the Federal Government. Located within the National Institutes of Health, NCI is charged with conducting a comprehensive program of research to identify and promote ways to reduce the burden of cancer. To that end, NCI conducts research on cancer risk factors, advancement of treatment and diagnosis, and development of prevention and control methods. NCI seeks to design effective strategies for disseminating information on research results to the public and the Nation's health professionals.

The Office of Special Populations Research (OSPR) is located within the Office of the Director, NCI. OSPR was established in June 1996 to advise and guide the Director of NCI on policy, programs, research, and issues pertaining to special populations. The reason for creating this Office was to ensure that the cancer problem in special populations (e.g., minorities, underserved individuals, and elderly persons) is adequately addressed. The Office also provides continued leadership at the Federal Government level in addressing cancer research, programmatic, and outreach needs for special populations. Thus, OSPR serves as a focal point to provide leadership and coordination of research related to minorities and special populations.

In 1981, NCI set forth principles for cancer control research on targeted populations. In 1985, the Secretary of Health and Human Services' Task Force on Black and Minority Health strongly encouraged research on the effectiveness of strategies for health system intervention and preventive services in minority communities *(3)*. In 1986, NCI created the Special Populations Studies Branch (SPSB) within the Cancer Control Science Program (now called the Division of Cancer Control and Population Sciences), with the charge to reduce and eliminate differences in cancer incidence, mortality, and survival between minority and special populations and the general population. In 1989, the two initiatives (RFAs) that resulted in the funding of the avoidable mortality and primary prevention studies were introduced by the SPSB staff.

GOALS AND OBJECTIVES OF THE NATIVE AMERICAN STUDIES

Avoidable Mortality From Cancer in Native American Populations

Prevention of Cervical Cancer in Alaska Native Women

The goal of the Alaska Native women's study was to reduce morbidity and mortality from cervical cancer among Alaska Native women age 20 and older. The project objectives were to (1) assess knowledge of and attitudes about cervical cancer, its causes, early detection, and treatment; (2) determine the frequency (prevalence) of Pap testing; (3) assess attitudes and satisfaction regarding cancer prevention services, particularly the Pap test; (4) identify barriers to preventive health care; (5) increase the availability of women's health services, particularly services offered by female practitioners; (6) improve the followup of women with abnormal Pap tests; and (7) develop culturally appropriate educational materials. In this monograph, this project is also referred to as the "Women's Health Project."

North Carolina Native American Cervical Cancer Prevention Project

The North Carolina Native American women study's goal was to reduce cervical cancer mortality among American Indians. The primary objective was to increase the proportion of women age 18 and older who received Pap smears at appropriate intervals and who returned for followup care when necessary. The study was implemented in two North Carolina populations of American Indians, the Eastern Band of the Cherokee and the Lumbee.

The Wai`anae Coast Cancer Research Project

The goal of the Wai`anae study was to reduce the disproportionate cancer mortality from breast and cervical cancers among Native Hawaiian women. The study objectives were to (1) test the effectiveness of a culturally sensitive intervention as a means of increasing breast and cervical cancer screening practices; and (2) increase knowledge, attitudes, and behavior scores among Native Hawaiian women. This project targeted women 18 years of age and older.

Primary Prevention of Cancer in Native American Populations

Tobacco Policy Intervention in Northwest Indian Tribes

The goal of the tobacco policy study was to change tribal policies so as to alter individual smoking behavior and to help protect individuals from exposure to tobacco smoke. The objectives were to (1) develop a consultative process that assisted Indian tribes in creating and implementing more explicit, comprehensive, and stringent tobacco use policies; (2) evaluate the process by means of a prospective randomized design that assigned tribes to immediate or delayed intervention; (3) assess the impact of policy intervention on smoking knowledge, norms, attitudes, intentions, and behavior among influential tribal leaders; (4) evaluate the relationship of tobacco use

policies and level of antitobacco behavior; and (5) develop a manual and set of guidelines for tobacco policy councils and organizations.

Smoking Cessation for American Indians

The smoking cessation study's goal was to increase long-term smoking cessation among American Indian populations in northern California through a reproducible

clinic-based program. The objectives were to (1) identify needs and barriers related to smoking cessation; (2) estimate the prevalence of smoking and smokeless tobacco use and the correlates of those behaviors among American Indian clinic users in northern California; (3) modify the previously tested, physician-initiated self-help smoking cessation model for the American Indian health clinic setting; and (4) evaluate the effectiveness of the intervention. This study targeted American Indians age 18 and older. In this monograph, this study is also referred to as the "It's Your Life—It's Our Future Smoking Cessation Project."

Southwestern Cancer Prevention Project for American Indians

The Pathways to Health study's goal was to promote healthy lifestyle behaviors among fifth- and seventh-grade students from several Indian tribes in New Mexico. The primary objective was to develop, implement, and evaluate a multidisciplinary program designed to promote the avoidance of cigarette smoking and smokeless tobacco use and to encourage consumption of a low-fat, high-fiber diet for students and their families. In this monograph, this study is also referred to as the "Pathways to Health Project."

Reducing Cancer Risks Among Native American Adolescents

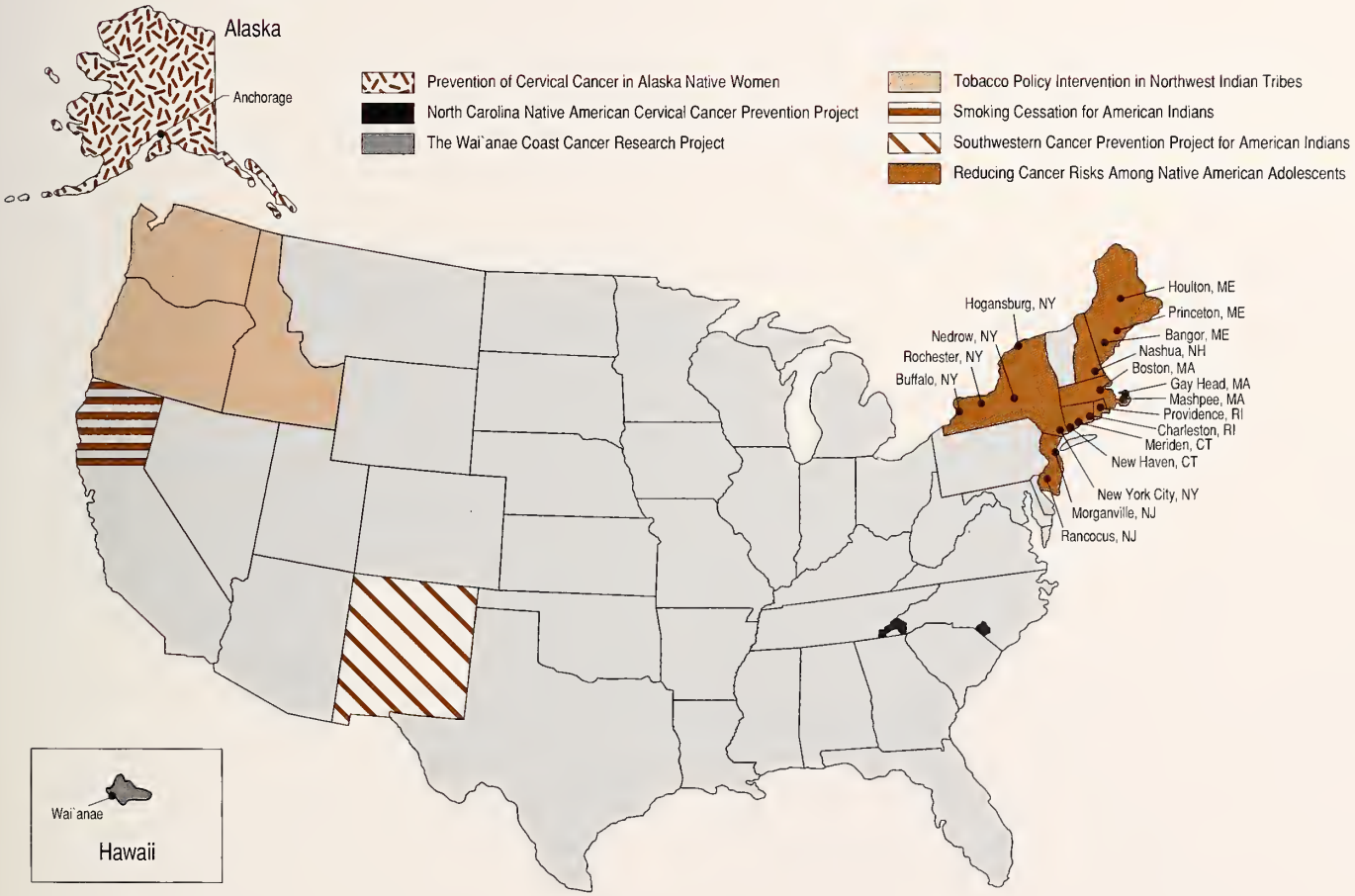
The goal of the Native American adolescents study was to advance the science of cancer risk reduction interventions for younger American Indians. The primary objective was to study the efficacy of an intervention to prevent tobacco use and modify dietary habits among American Indian youth in seven northeastern states.

HIGHLIGHTS OF RESULTS FROM THE NATIVE AMERICAN STUDIES

Native Americans face a significant gap between cancer prevention and control needs and existing services. The NCI-funded studies represent a major step toward closing that gap.

As shown in Figure 1, the studies, although concentrated mainly in the western part of the United States—Hawaii, Alaska, Oregon, New Mexico, and California—were also located in the Northeast and Southeast, New York, and North Carolina, respectively. Thus, a wide spectrum of Native Americans, including many Indian tribes, Native Hawaiians, and Alaska Natives, benefited from these studies in their respective communities. The results from these studies can be adapted for other Native Americans in other States and regions. Each chapter in this monograph contains sufficient details about how these studies were conducted so they may be repli-

Figure 1: Location of NCI-Supported Native American Studies



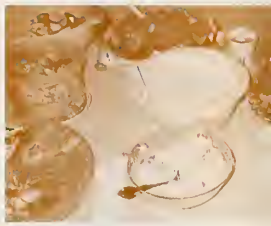
cated in other Native American communities.

It should be noted that the studies varied in terms of study topic, approach, site, and methodology. Some involved methods to increase breast and cervical cancer screenings; others involved interventions to prevent the onset of smoking behavior and smoking cessation programs; still others were school-based interventions to prevent and control tobacco use and modify diets; and one intervention changed tribal smoking policies. The settings for these studies were communities, tribes, clinics, and schools.

The research design used by most of the research teams was a pretest-posttest design. Although this design is useful for determining some change as a result of an intervention, it is not as robust as an experimental design that uses an experimental and a control group to determine the impact of an intervention on knowledge, attitudes, and behavior.

These studies received widespread support among Native American people because Native Americans were involved in every phase of the studies. Culturally sensitive approaches and materials were used, and each study included Native Americans on the research team. Native Americans served as advisers to the studies, and community leaders were also consulted. Several of the studies (e.g., those in Hawaii, California, New Mexico, North Carolina, and Alaska) used focus groups to help plan, develop, and implement the interventions.

For example, the Hawaii study's use of focus groups resulted in use of the kokua group intervention because the focus group believed that method would be most effective in their community. *Kokua* is defined as a mutual willingness to help others without an expectation of return. The kokua intervention, delivered by trained Native Hawaiian health educators in a group setting, consisted of education to increase breast and cervical cancer screenings in the Native Hawaiian community. After the kokua group intervention, study participants showed positive gains in knowledge, and a significant number of women at posttest indicated that they were planning to get a Pap test and mammogram.



Focus groups also helped the California smoking cessation study increase its cultural sensitivity to the Native American community. Focus group sessions were conducted to determine beliefs, barriers, and smoking cessation methods that would be acceptable in these communities. Results from the study show that 30 percent of smokers at clinics promoting the smoking cessation program attempted to quit smoking during the study, in contrast to 20 percent of those at clinics providing standard care.

During the 2 years that its curriculum (intervention) was being developed, pilot-tested, and revised, the New Mexico study team held separate focus groups with American Indian teachers, parents, and school administrators from participating schools to elicit their advice on key cultural concepts and appropriate methods for use in their schools and communities. One finding of the study was that seventh-grade intervention students reported higher lev-

els of cigarette use at posttest than at pretest. The research team surmised that this may have been because seventh graders participated in ceremonial activities that included traditional tobacco use. These results indicate that the sixth grade may be a critical transitioning period for American Indian students in regard to behavioral intentions to begin tobacco use.

An important lesson learned from the New York study, which also focused on American Indian youth, was that an integrated approach, utilizing both tobacco use prevention and dietary modification, promoted better outcomes than an isolated approach. The target population for this study—fourth, fifth, sixth, and seventh graders—was not a captive audience of classroom students as were students in the New Mexico study. The New York youths were recruited from the community.

Both the Hawaii and North Carolina studies used Native American lay health educators to deliver their interventions. The North Carolina intervention was delivered to women during two personal visits to their homes. Results from the North Carolina study indicated that the Cherokee women had increased knowledge after the intervention and were more likely than women in the control group to report obtaining a Pap smear during the preceding year. The Lumbee women also had increased knowledge and behavioral intentions but were less likely to obtain Pap smears than the control group.

The Tobacco Policy Intervention in Northwest Indian Tribes study (Washington, Oregon, and Idaho) used a unique cancer prevention and control method. The approach relied heavily on the structure and political independence of Indian tribes, which the research team thought was applicable to reducing other health risk factors. The changes resulted in stronger smoking policies, and the number of tribes with smoke-free policies doubled during the intervention.

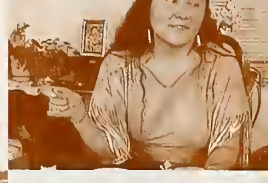
Finally, the Alaska study documented the lack of accurate Pap test data for Native women. Before the study was implemented, there were few data on how frequently Native women received a Pap test and on the knowledge, attitudes, and behavior of Alaska Native women with respect to cervical cancer. The Alaska study addressed this problem. Results from the study show that among participants in the Alaska study, the percentage of women who had not had a Pap test declined from 48 percent to 20 percent. In contrast, there was little improvement in screening among the control group (i.e., those who had not participated in the study).

RESEARCH INTERVENTION APPROACHES

Few studies address cancer control intervention models in Native American communities, and even fewer document those that are successful in reaching the project's goals *(4)*. To address this need, those research projects and interventions that are effective in Native American communities must be identified. The NCI Native American research projects reviewed in this monograph can be used as building blocks for further innovative research that will directly address the health needs of Native populations.

Table 1 illustrates the four major intervention approaches used in the design of the cancer prevention and control projects in Native populations. These approaches are identified as policy change, educational change, behavioral change, and replication of intervention models. Although these approaches are not mutually exclusive, they illustrate the different methods used in the design and implementation of the projects.

The following section highlights important categories and approaches that were fundamental to the projects.



Policy Change

Policy change is defined as an overall plan embracing general goals and acceptable procedures, especially of a governmental body *(5)*. Policy change is often the most difficult approach because it takes a longer period of time to implement and to measure results. Although harder to achieve, policy change often has longer lasting results. The Northwest project implemented a tobacco policy approach that affected tobacco control in the area of restricting abusive smoking practices. This program also took advantage of community involvement and advocacy for public smoking restrictions with tribes in Idaho, Washington, and Oregon. The Northwest project successfully targeted tobacco policy changes aimed at restricting abusive smoking behavior in tribal facilities and in tribal community gatherings.

Tobacco has had a long and important history among many tribes. Revered for its spiritual and ceremonial use, tobacco was used for trade with early colonists. Today, tribes continue to use tobacco ceremonially and to benefit economically from the tobacco industry *(6)*. Thus, implementing an intervention that examines and changes longstanding tobacco practices involves educating the Indian community and tribal counsels on the benefits of the policy change. It also involves working with the community to develop and implement the changes. The resulting policy, setting up smoke-free tribal areas, was identified as instrumental in setting the stage for future programs of smoking cessation and tobacco control that were successful in Native communities.

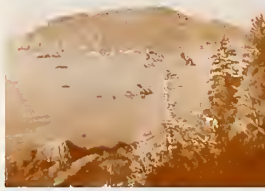


TABLE 1: Research Intervention Approaches in Native Populations

Project	*Approaches*			
	Policy	Educational	Behavioral	Replication
Alaska		X		
North Carolina		X		
Hawaii			X	
Northwest	X			
California		X		X
Southwest		X		
Northeast		X		

Educational Change

Educational change includes those teachings that increase an individual's level of knowledge. The educational interventions presented in this monograph are similar in their use of role models along with educational material to promote positive change. In this approach, respected peers or community members often serve as role models to promote positive behavior and to enhance the acceptance of educational material. Testimonials are often the basis for the presentation. Various media approaches—video, television, radio, tape recordings, and printed materials—also are used to enhance education and knowledge.

The projects in Alaska, North Carolina, the Northeast, and the Southwest used educational intervention models in their prevention programs. The Alaska project designed cervical cancer educational materials with illustrations of Native Alaskan stylized dancers; these informational reading materials detailed when and where to get a Pap test. The materials included information on where and why Native women should seek cancer screening. Likewise, the North Carolina project developed educational materials in a format acceptable and culturally sensitive to the target population.

A smoking cessation videotape, *It's Your Life,* highlighted testimony by American Indians and Alaska Natives on the negative effects of smoking. The video played a significant role in the California project, providing the motivational support to quit smoking. A self-help guide, emphasizing quitting methods ("slow turtle" or the "cold turkey"), accompanied the video. A video produced by the Southwest project played a significant part in presenting the cancer prevention message to both students and their families. This video, *Life in Balance,* includes the testimony of six American Indian adults who are regarded as role models in their communities, describing their personal journeys to reach a more healthful balance in their lives through healthy lifestyle choices.

Peer education, provider training, and community involvement were the overarching strategies in both the tobacco projects and the cervical cancer projects. The Native community easily identified and accepted the health information as culturally appropriate and important. To further involve the community, the projects employed Native community members to present the educational materials.

Behavioral Change

Modifying the response or action of an individual or group is the result of behavioral change. The strategy used by the Hawaii project incorporated designing and implementing a culturally sensitive intervention as a means of increasing breast and cervical cancer screening practices, thus changing behaviors. The kokua group is the name of the primary intervention created for this project. The project used traditional Hawaiian values and communication patterns as the basis for an educational curriculum that promotes breast and cervical cancer screening among Native Hawaiian women. Positively changing the behavior of Native Hawaiian women in cancer screening took place through the diffusion of information and support that occurred in the community. This model incorporated traditional Hawaiian practices—i.e., the health navigator leading Native Hawaiian women to the project and assisting them in promoting their well-being through appropriate health screening examinations.

Replication of Intervention Models

Replicating tried and true intervention models is a common approach to addressing community health needs. Rather than "reinventing the wheel," this approach identifies projects and interventions that were reported as successful in a cultural setting. Project staff then adapt all or portions of the model to fit the specific needs of the community. Refinement or reassessment of the model is sometimes necessary, especially when working with Native communities, to make the intervention culturally appropriate and accessible.

The California project was based on NCI's stop-smoking model. This NCI model trained physicians and other providers to counsel patients to quit smoking and to monitor and assist them in that decision *(7)*. Important to the program was the establishment of clinic protocols for recordkeeping, for patient monitoring of the stages of cessation, and for improving patient appointment-keeping and involvement in health care.

The Indian clinics are often seen as the focus of Indian communities in California. Because this population identified smoking cessation as a priority for research, the research team was able to adapt an NCI smoking model to the Indian community by involving Indian clinic providers and Indian health workers from the community. Using the strength of the Native community by subcontracting Indian health staff, such as community health representatives, and revising the smoking cessation message to include important cultural values, beliefs, and cues to action, became important aspects of adapting the model. The design and content of the smoking cessation materials were tailored to the Native community.

CONCLUSION

A review of the NCI Native American research projects identified four major intervention approaches: policy change, educational change, behavioral change, and replication of current intervention models that achieved favorable results in Native communities. The similarities and differences among these approaches were examined, and the steps taken within each research project for achieving successful community collaboration and project implementation were documented by the authors.

In designing an appropriate cancer intervention project, researchers must consider those approaches to cancer prevention and control that work and those that are culturally appropriate and acceptable to Native communities. The authors suggest that effective interventions in Native communities should be customized to the specific culture of the target population. Working within the Native community in the planning, design, and implementation phases will produce more effective and acceptable interventions and lead to success in completing project goals.

This monograph has moved our efforts closer to a clearer understanding of successful cancer prevention and control interventions among American Indians, Alaska Natives, and Native Hawaiians. Nevertheless, there continues to be an overwhelming need to continue research efforts in the areas of tobacco control and cessation, nutrition, and breast and cervical cancers.

The four primary prevention projects targeting tobacco control and cessation and nutrition provided significant information on the role of culture, both as a facilitator and as a barrier to smoking cessation and control. The Northwest project demonstrated the success of working within the culture of the target population, developing and implementing policies at the tribal level. The California project also worked with the Native population in providing a culturally sensitive intervention. However, the American Indian traditional values of noninterference and respect for independence were shown to promote more lenient attitudes and behaviors toward smoking. The Southwest

and Northeast projects expanded our knowledge about cancer risk behaviors among Native youth. These projects documented early experimentation with smoking and recommended the importance of using an integrated approach, targeting tobacco and diet, to promote overall health and well-being. Given that the highest smoking prevalence is reported among American Indians and Alaska Natives in comparison to non-Indians *(8)*, and that smoking is one of the most preventable risk behaviors for cancer, interventions of this nature are paramount in improving the health of Native populations.

Among all the projects, cultural sensitivity in the planning, implementation, and evaluation of projects was significant to their success. Cervical cancer is a serious health concern in all Native communities because of high morbidity and poor 5-year survival rates *(9)*. Breast cancer rates, which are very high among Native Hawaiians and Alaska Natives, are of particular concern *(10)*. These projects demonstrated their innovative approach to health education and prevention intervention, showing that culturally sensitive interventions can make a difference in influencing cancer risk behaviors. The Alaska project tailored educational materials on cervical cancer specifically to the Alaska Native culture and included Alaska Natives in the planning and implementation of the project. The North Carolina project found that using community resources and staff increased the acceptability and credibility of the intervention. The Hawaii project's cultural approach of using a traditional Hawaiian method of group support and interaction was significant to the success of the project. The Hawaii project used kokua groups as the basis for merging cultural identity with the intervention to form support groups receptive to learning and changing behaviors.

This monograph is a tangible product that can be of great use to Native communities. The information from these research projects can lead to more successful program planning and interventions that are more adaptable and acceptable to Native populations. These NCI projects are working models that can be replicated and have a positive effect on the health and well-being of Native American communities.

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APPENDIXES

Highlights of Avoidable Mortality From Cancer in Native American Populations Program

	Site 1	*Site 2*	*Site 3*
Project title:	Prevention of Cervical Cancer in Alaska Native Women	North Carolina Native American Cervical Cancer Prevention Project	The Wai`anae Coast Cancer Research Project
Name of organization:	Alaska Area Native Health Service	Wake Forest University School of Medicine	The Wai`anae Coast Comprehensive Health Center
Location of site:	Anchorage, AK	Winston-Salem, NC	Wai`anae, HI
Type of cancer screening targeted:	Cervical	Cervical	Breast and cervical
Group studied:	Alaska Native women	American Indian women	Hawaiian women
Age of study group:	20 and older	18 and older	18 and older
Control group:	Yes	Yes	No
Number in study:	481 urban women	1,020 Cherokee women 983 Lumbee women	500
Primary objective of project:	Promote knowledge and awareness of cervical cancer, its risk factors, and screening programs. Determine the number of women receiving Pap test	Increase proportion of women 18 and older who receive Pap smears at appropriate intervals and return for followup care when necessary.	Test effectiveness of a culturally sensitive, community-driven intervention as a means of increasing breast and cervical cancer screening practices, as well as increase KAB scores among Native Hawaiian women.

Highlights of Avoidable Mortality From Cancer in Native American Populations Program

	Site 1	*Site 2*	*Site 3*
Study design:	Provision of clinic services and education about cervical cancer and screening	Use of tribal rolls to select individuals randomized to four groups	Formation of health-activated mutual support groups (kokua groups)
Comparison of intervention and control groups at baseline and later:	Yes	Yes	
Comparison of same intervention group at baseline and later:	Yes	Yes	
Type of intervention:	Clinic	Tribal	Community
Data collection method:	Face-to-face interviews and surveys; medical record review	Household interviews	Self-administered questionnaire
Percent improvement in screening rates attributable to intervention:	Alaska Native women who had one or more Pap tests increased from 41 percent to 49 percent pre- and postintervention, respectively. There was a significant increase in women's knowledge of cervical cancer, risk factors, and screening.	Approximately 73 percent of all Cherokee women who received the intervention reported having a Pap test in the past year, compared to 64 percent of women who did not receive the intervention (adjusted odds ratio [OR] = 2.06, 95% confidence interval [CI] = 1.14-3.72). Among the Lumbee women, there was no significant intervention effect on the number of women who reported having received a Pap test in the past year.	With respect to having a Pap test, 29 percent of the women reported that they were planning to make an appointment (compared to 19 percent pre-kokua group) and 64 percent said they were in adherence (compared to 59 percent pre-kokua group). This contrast was significant ($z = -5.45$, $p < .001$) by Wilcoxon signed rank test.

Highlights of Primary Prevention of Cancer in Native American Populations Program

	Site 4	*Site 5*	*Site 6*	*Site 7*
Project title:	Tobacco Policy Intervention in Northwest Indian Tribes	Smoking Cessation for American Indians	Southwestern Cancer Prevention Project for American Indians	Reducing Cancer Risks Among Native American Adolescents
Name of organization:	Oregon Research Institute	Center for American Indian Research and Education	University of New Mexico	Columbia University
Location of site:	Eugene, OR	Berkeley, CA	Albuquerque, NM	New York, NY
Target health behavior:	Tobacco use policy	Smoking cessation	Avoidance of smoking and smokeless tobacco; low-fat, high-fiber diet	Tobacco use and dietary modification
Group studied:	39 tribes in Northwest	American Indian clinic users in northern California	Navajo and Pueblo Southwest Indian tribes	Native American adolescents
Age of study group:	Tribe unit of analysis	18 and older	5th- and 7th-grade students and their families	8 to 13 years
Number in study:	39 tribes	1,369	1,589	135
Intervention group:	19 tribes in early intervention, 20 in late intervention	695		103

Highlights of Primary Prevention of Cancer in Native American Populations Program

	Site 4	*Site 5*	*Site 6*	*Site 7*
Control group:		669		31
Primary objective of project:	Develop a consultative process to facilitate tribes in creating and implementing more explicit and stringent tobacco use policies; assess impact of policy intervention and evaluate relationship of tobacco use policies and antitobacco behavior; develop a manual and guidelines for tobacco policy development and implementation for use by tribal councils and organizations	Increase long-term smoking cessation among American Indian populations through a reproducible clinic-based program	Develop, implement, and evaluate a program to promote avoidance of smoking and use of smokeless tobacco and promote a low-fat, high-fiber diet	Reduce cancer risks among Native American youth by developing skills to resist pressures to use tobacco or eat poorly
Control group:	No	Yes	Yes	Yes
Study design:	Randomization of tribes to immediate (early) or delayed (late) intervention following baseline assessment; continuous and dichotomous summary measures	Randomized clinical trial; matched pairs	*Pathways to Health* cancer prevention curriculum used	17 initial intervention sessions with semiannual booster sessions; four cells: (1) tobacco use prevention and dietary modification, (2) tobacco use prevention, (3) dietary modification, (4) no intervention. Urban and reservation sites
Comparison of intervention and control groups:		Yes	Yes	Yes—at baseline and semiannually

Highlights of Primary Prevention of Cancer in Native American Populations Program

	Site 4	*Site 5*	*Site 6*	*Site 7*
Comparison of same intervention group at baseline and later:		Yes	Yes	Yes
Type of intervention:	Tribal policy change	Clinic	School and family	Community
Data collection method:	Phone interview data on tobacco policies from 39 tribes at baseline and followup	Self-administered questionnaire at baseline; 6- and 18-month followup personal interviews in homes; process interviews	Questionnaires and body composition measures administered before and after curriculum	Pre- and posttest questionnaires; eating habit questionnaires; cotinine tests
Intervention outcomes:	Significant tobacco policy changes for both the tribes that received consulting help first and those that received consulting help later. Policies were stronger, and more tribes were smoke-free in all three common areas by the end of the program. The number of tribes having smoke-free policies in all three common areas more than doubled in both groups of tribes.	Mean quit rate in 6-month followup for intervention group was .1272 compared to mean control quit rate of .064. The difference between these two was significant ($p < .01$). The intervention had a greater effect on light smokers than on heavier smokers.	Baseline nutrition questionnaire shows students lack essential knowledge about dietary fat and fiber and relationship of diet to cancer risk. Use of smoking and smokeless tobacco and intent to use increased with grade level. Data confirm need for primary prevention studies for this population. Families and school personnel reported positive experiences with the program.	The combined tobacco use prevention and dietary modification intervention appears to have had the most success in influencing youths away from tobacco use and toward a more healthy diet.

SEER Incidence Rates, Men, 1988-1992

Cancer Site	*Alaska Native*	*American Indian*	*Hawaiian*	*Black*	*White*	*Hispanic*
All Sites	372.0	196.0	340.0	560.0	469.0	319.0
Brain & ONS	*	*	*	4.5	7.8	5.2
Colon & Rectum	79.7	18.6	42.4	60.7	56.3	38.3
Esophagus	*	*	9.4	15.0	5.4	4.4
Kaposi's Sarcoma	*	*	*	5.7	5.8	5.9
Kidney & Renal Pelvis	(19.0)**	15.6	9.8	12.8	11.9	10.0
Larynx	*	*	*	12.7	7.5	5.1
Leukemias	*	*	10.8	11.5	13.5	9.4
Liver & IBD	*	(13.1)**	*	6.9	3.7	6.7
Lung & Bronchus	81.1	14.4	89.0	117.0	76.0	41.8
Non-Hodgkin's Lymphoma	*	*	12.5	13.2	18.7	14.1
Hodgkin's Disease	*	*	*	2.3	3.3	2.5
Melanoma	*	*	*	1.0	14.5	2.7
Multiple Myeloma	*	*	*	11.3	5.0	4.2
Nasopharynx	*	*	*	1.0	0.6	0.6
Oral Cavity	*	*	11.7	20.4	14.6	8.9
Pancreas	*	*	10.9	14.0	9.8	8.0
Prostate	46.1	52.5	57.2	180.6	134.7	89.0
Stomach	27.2	*	20.5	17.9	10.2	15.3
Testis	*	*	*	0.8	5.0	2.9
Thyroid	*	*	*	1.4	2.6	2.0
Urinary Bladder	*	*	*	15.2	31.7	15.8

Note: *Rates are "average annual" per 100,000 population, age-adjusted to 1970 U.S. standard. * = rate not calculated when fewer than 25 cases; data source for American Indians is New Mexico. ( )** = Rates based on fewer than 25 cases are included only for the top five most frequently diagnosed cancers for ethnic group. These rates may be subject to greater variability than other rates which are based on larger numbers. ONS = other nervous system; IBD = intrahepatic bile duct.*

Source: *SEER Program, National Cancer Institute. Miller BA, Kolonel LN, Bernstein L, Young JJr, Swanson G, West D, et al., editors. Racial/ethnic patterns of cancer in the United States 1988-1992. SEER monograph. NIH Publication No. 98-4104. Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute, Cancer Control Research Program, 1998.*

SEER Incidence Rates, Women, 1988-1992

Cancer Site	*Alaska Native*	*American Indian*	*Hawaiian*	*Black*	*White*	*Hispanic*
All Sites	348.0	180.0	321.0	326.0	346.0	243.0
Brain & ONS	*	*	*	3.4	5.4	3.8
Breast	78.9	31.6	105.6	95.4	111.8	69.8
Cervix Uteri	15.8	9.9	9.3	13.2	8.7	16.2
Colon & Rectum	67.4	15.3	30.5	45.5	38.3	24.7
Corpus Uteri	*	10.7	23.9	14.4	22.3	13.7
Esophagus	*	*	*	4.4	1.7	0.9
Kidney & Renal Pelvis	(16.7)**	*	*	6.0	5.9	5.5
Larynx	*	*	*	2.5	1.5	0.7
Leukemias	*	*	7.2	6.8	7.9	6.4
Liver & IBD	*	*	*	2.4	1.5	2.6
Lung & Bronchus	50.6	*	43.1	44.2	41.5	19.5
Non-Hodgkin's Lymphoma	*	*	*	7.6	12.0	9.1
Hodgkin's Disease	*	*	*	2.0	2.6	1.6
Melanoma	*	*	*	0.7	10.1	3.2
Multiple Myeloma	*	*	*	7.4	3.2	3.0
Nasopharynx	*	*	*	*	0.2	*
Oral Cavity	*	*	*	5.8	5.8	2.7
Ovary	*	17.5	11.8	10.2	15.8	11.4
Pancreas	*	*	8.7	11.5	7.4	6.9
Stomach	*	*	13.0	7.6	4.4	8.0
Thyroid	*	*	9.1	3.3	6.5	6.2
Urinary Bladder	*	*	*	5.8	7.8	4.3
Gallbladder	*	13.2	*	*	*	*

Note: *Rates are "average annual" per 100,000 population, age-adjusted to 1970 U.S. standard. * = Rate not calculated when fewer than 25 cases; data source for American Indians is New Mexico. ( )** = Generally rates based on fewer than 25 cases are included only for the top five most frequently diagnosed cancers for ethnic group. These rates may be subject to greater variability than other rates which are based on larger numbers. ONS = other nervous system; IBD = intrahepatic bile duct. Rates for gallbladder appear only for American Indian women.*

Source: *SEER Program, National Cancer Institute. Miller BA, Kolonel LN, Bernstein L, Young J Jr, Swanson G, West D, et al., editors. Racial/ethnic patterns of cancer in the United States 1988-1992. SEER monograph. NIH Publication No. 98-4104. Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute, Cancer Control Research Program, 1998.*

SEER Mortality Rates, Men, 1988-1992

Cancer Site	*Alaska Native*	*American Indian*	*Hawaiian*	*Black*	*White*	*Hispanic*
All Sites	225.0	123.0	239.0	319.0	213.0	129.0
Brain & ONS	*	*	*	3.1	5.4	3.0
Colon & Rectum	27.2	(8.5)**	23.7	28.2	22.9	12.8
Esophagus	*	*	*	14.8	5.3	3.4
Kidney & Renal Pelvis	(13.4)**	*	*	5.1	5.0	3.7
Larynx	*	*	*	5.6	2.3	1.9
Leukemias	*	*	7.8	8.0	8.5	5.1
Liver	*	(11.2)**	9.2	6.6	3.8	5.9
Lung & Bronchus	69.4	(10.4)**	88.9	105.6	72.6	32.4
Non-Hodgkin's Lymphoma	*	*	8.8	5.8	8.1	5.3
Hodgkin's Disease	*	*	*	0.7	0.7	0.6
Melanoma	*	*	*	0.5	3.4	0.8
Multiple Myeloma	*	*	*	7.3	3.4	2.7
Nasopharynx	(11.6)**	*	*	0.6	0.3	0.3
Oral Cavity	*	*	*	8.7	3.8	2.7
Pancreas	*	*	12.8	14.4	9.7	7.1
Prostate	*	16.2	19.9	53.7	24.1	15.3
Stomach	(18.9)**	(11.2)**	14.4	13.6	6.1	8.4
Testis	*	*	*	0.1	0.3	0.2
Thyroid	*	*	*	0.3	0.3	0.2
Urinary Bladder	*	*	*	4.8	5.8	2.8

Note: *Rates are "average annual" per 100,000 population, age-adjusted to 1970 U.S. standard. * = Rate not calculated when fewer than 25 deaths; data source for American Indians is New Mexico. ( )** = Rates based on fewer than 25 deaths are included only for the top five most common types of cancer death for ethnic group. These rates may be subject to greater variability than other rates which are based on larger numbers. ONS = other nervous system; IBD = intrahepatic bile duct.*

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SEER Mortality Rates, Women, 1988-1992

Cancer Site	*Alaska Native*	*American Indian*	*Hawaiian*	*Black*	*White*	*Hispanic*
All Sites	179.0	99.0	168.0	168.0	140.0	85.0
Brain & ONS	*	*	*	2.1	3.7	2.0
Breast	(16.0)**	(8.7)**	25.0	31.4	27.0	15.0
Cervix	*	(8.0)**	*	6.7	2.5	3.4
Colon & Rectum	24.0	*	11.4	20.4	15.3	8.3
Corpus Uteri	*	*	8.4	6.0	3.2	2.3
Esophagus	*	*	*	3.7	1.2	0.7
Kidney & Renal Pelvis	(7.4)**	*	*	2.2	2.3	1.7
Larynx	*	*	*	0.9	0.5	0.2
Leukemias	*	*	*	4.6	5.0	3.4
Liver & IBD	*	*	*	2.7	1.8	2.8
Lung & Bronchus	45.3	*	44.1	31.5	31.9	10.8
Non-Hodgkin's Lymphoma	*	*	*	3.4	5.3	3.6
Hodgkin's Disease	*	*	*	0.4	0.4	0.3
Melanoma	*	*	*	0.4	1.7	0.5
Multiple Myeloma	*	*	*	5.0	2.2	1.8
Nasopharynx	*	*	*	0.2	0.1	0.1
Oral Cavity	*	*	*	2.1	1.5	0.7
Ovary	*	(7.3)**	7.3	6.6	8.1	4.8
Pancreas	(15.5)**	(7.4)**	9.1	10.4	6.9	5.2
Stomach	*	*	12.8	5.6	2.8	4.2
Thyroid	*	*	*	0.4	0.3	0.5
Urinary Bladder	*	*	*	2.4	1.7	0.9
Gallbladder	*	(8.9)**	*	*	*	*

Note: *Rates are "average annual" per 100,000 population, age-adjusted to 1970 U.S. standard. * = Rate not calculated when fewer than 25 deaths; data source for American Indians is New Mexico. ( )** = Rates based on fewer than 25 deaths are included only for the top five most common types of cancer death for ethnic group. These rates may be subject to greater variability than other rates which are based on larger numbers. ONS = other nervous system; IBD = intrahepatic bile duct. Rates for gallbladder appear only for American Indian women.*

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